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# BMJ Open

## Sacrifice and Solidarity: Family Experiences of Death and Bereavement During the Pandemic

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## **Sacrifice and Solidarity: Family Experiences of Death and Bereavement During the Pandemic**

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for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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## Summary Boxes

### Section 1: What is already known on this topic

Facilitating a personalized and connected environment for compassionate end-of-life care for hospitalized patients has seldom been more challenging than during the COVID-19 pandemic.

Social media and news reports have outstripped scientific study of the experience of losing a loved one during the pandemic. From the small pool of evidence generated to date, we know families suffer as a consequence of restrictive hospital policies leading to forced separation.

Given the tension between pandemic public health mandates and the desire of many relatives to visit their hospitalized family member, the objective of this study was to understand experiences of loss and bereavement for families of dying patients during the pandemic and garner suggestions for comforting practices in this context.

### Section 2: What this study adds

Profound loss and enduring grief were experienced by family members whose final connections to their loved one were subverted by pandemic restrictions. Our work contrasts previous reports describing tension and diminished trust between families and critical care staff, instead highlighting acceptance of pandemic-related restrictions for the public good and overall solidarity with the clinical team.

Frequent, flexible, and transparent communication is necessary to alleviate distressing images of patients in isolation or dying alone. Special attention is needed for patients whose isolation is intensified by sensory or functional impairment or limited technologic access.

Targeted efforts to promote individualized end-of-life were valued, including bringing personal items into the room, playing music, and modest but meaningful keepsakes such as finger-print keychains, word clouds, or knitted blankets.

**ABSTRACT**

**Background:**

Pandemic-related restrictions are expected to continue to shape end-of-life care and impact the experiences of dying hospitalized patients and their families.

**Objective:**

To understand families' experiences of loss and bereavement during and after the death of their loved one amidst the SARS-CoV-2 (COVID-19) pandemic.

**Design:**

Qualitative descriptive study.

**Setting:**

Three acute care units in a Canadian tertiary care hospital.

**Participants:**

Family members of 28 hospitalized patients who died from March-July 2020.

**Main outcome measures:**

Qualitative semi-structured interviews conducted 6-16 months after patient death inquired about family experiences before and beyond the death of their loved one, and garnered suggestions to improve end-of-life care.

**Results:**

Pandemic restrictions had consequences for families of dying hospitalized patients. Most family members described an attitude of acquiescence, some framing their experience as a sacrifice made for the public good. Families appreciated how clinicians engendered trust in the name of social solidarity while trying to mitigate the negative impact of family separation. However, fears about the patient's experience of isolation and changes to post-mortem rituals also created despair and contributed to long-lasting grief.

**Conclusion:**

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3 Profound loss and enduring grief were described by family members whose final connections to  
4 their loved one were constrained by pandemic circumstances. Families observed solidarity  
5 among clinical staff, and experienced a sense of unity with staff, which alleviated some distress.  
6 Their suggestions to improve end-of-life care given pandemic restrictions included frequent,  
7 flexible communication, exceptions for family presence when safe, and targeted efforts to  
8 connect patients whose isolation is intensified by functional impairment or limited technologic  
9 access.  
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### 14 15 **Strengths and Limitations of this Study**

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19 Strengths of this study include a focus on family experiences of loss and bereavement both  
20 within and beyond hospital exposure.  
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24 Results from this work garnered suggestions for improving end-of-life care during pandemic  
25 times, which included frequent, flexible, and transparent communication to help alleviate  
26 distressing images of patients dying alone as well as targeted attention for patients with  
27 language barriers or physical and/or cognitive impairments, who are especially impacted by the  
28 absence of their family.  
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34 This study extends prior work in a larger sample of 28 families in the North American setting,  
35 with a higher participation rate and range of relationships.  
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39 Limitations include a predominantly white, English-speaking sample from the first pandemic  
40 wave in the context of a publicly-funded healthcare system.  
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43 Results may differ for individuals with more videoconferencing access and ability, in  
44 communities with a different COVID-19 prevalence and vaccination penetrance, and in different  
45 healthcare systems.  
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**Introduction**

As mortality associated with serious SARS-CoV-2 (COVID-19) infection continues,<sup>1-5</sup> so do public health measures that restrict family presence in hospital.<sup>6</sup> Minimal personal contact and maximal barrier precautions profoundly affect the experiences of living, visiting and dying in hospital.<sup>6</sup> While facilitating an intimate environment for compassionate end-of-life care can be difficult at the best of times, the COVID-19 pandemic has made providing personalized care for dying patients and their families more challenging.<sup>7-10</sup>

With ongoing infection rates, pandemic restrictions are expected to impact hospitalized patients, their families, and healthcare providers for months to come.<sup>11</sup> Research is beginning to emerge directly from family members on the impact of losing a loved one during the pandemic.<sup>12-17</sup> In a Veterans Affairs (VA) survey, families of dying patients in acute hospital care, nursing home, and hospice settings reported poor communication with the healthcare team and fear of patients dying alone as leading contributors to their experiences of distress.<sup>15</sup> Other qualitative work investigating the experiences of grieving family members describe suffering driven by the separation from their loved ones, an inability to establish strong bonds with staff, and an interruption of common death rituals.<sup>12 16</sup> The forced separation of patients from their family has also troubled clinicians worldwide.<sup>10 18-21</sup>

Given the tension between pandemic public health mandates and the desire of many relatives to visit their hospitalized family member, the objective of this study was to understand experiences of loss and bereavement for families of dying patients during the pandemic and garner suggestions for comforting practices in this context.

**Methods**

In this qualitative study, we contacted families of patients who died in hospital during the first wave of the COVID-19 pandemic between March 16 to July 1, 2020 in three acute care units (ICU, medical step down, COVID-19 ward) at a university-affiliated hospital in Canada. Following a study of hospital-based clinicians to understand adaptations to end-of-life care during the pandemic <sup>10</sup>, family members of those patients were invited by telephone to an interview to understand how their experience of loss and bereavement was influenced by the pandemic. We attempted to recruit one family member or friend as the designated next-of-kin

for each patient based on documentation in the medical chart. Family member recruitment was delayed 6-12 months after the patient's death to honour the anticipated grieving process.

Employing qualitative description methods,<sup>22</sup> we used a semi-structured interview guide developed and piloted with our interprofessional research team (supplementary appendix). Domains included: general experiences of loss and bereavement; influences of pandemic-related hospital policies; videoconferencing technology, and memorial rituals. Interviews were conducted by two trained interviewers (BD, MS). Participants were given the choice of being interviewed by telephone or videoconferencing, and of having their interview audio-recorded or having notes taken in place of recording. Their demographic data were captured using open-ended questions.

### *Data Analysis*

Transcripts were analyzed using conventional qualitative content analysis.<sup>22 23</sup> After an initial phase of open coding to condense and summarize the data, focused codes were developed through discussion with the research team. New data were compared to emerging analytic concepts for refinement using a constant comparative approach <sup>24</sup> during serial investigator meetings. Descriptive statistics were used to quantitatively summarize family demographic data.

### *Ethics*

Local research ethics approval was obtained from the Hamilton Integrated Research Ethics Board (HiREB-11005) and all interviewees provided informed consent.

### *Role of Funding*

This study received peer-review funding by Physicians Services Incorporated of Ontario (Grant R21-16), McMaster University Paul O'Byrne Research Grant, and the Canadian Institutes for Health Research. The funders had no role in study design and conduct of the study; collection, management, analysis, and interpretation of the data; or preparation, review, or approval of the manuscript.

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*Patient and Public Involvement*

Patient and public involvement were sought during the development of the 3 Wishes Project (3WP) study protocol. The 3WP which is an end-of-life intervention aimed to honour dying patients at the end of life. The 3WP has grown into a program of research aimed at improving EOL across critical and acute care settings.<sup>25</sup> Many studies have emerged from the larger 3WP program of research, including the work presented in this article. Due to expedited study processes during COVID-19, dying patients, their loved ones, and the public were not directly involved in the design of this project.

## RESULTS

### *Participants*

Of 45 deceased patients included in the original study,<sup>10</sup> we were unable to locate a surrogate decision-maker for 7 patients (e.g. no family, changed addresses, no telephone). We contacted family members for 38 patients (Figure 1). Of these, 7 (18.4%) declined to participate, 1 due to lack of interest and 6 explaining their difficulty coping with the death of their loved one. Of 31 family members who agreed to participate, 3 (9.7%) interviews were not completed due to loss to follow-up. Of 28 family members interviewed, 2 were partners, 4 were parents, 14 were children, and 8 had other relationships with the deceased (Table 1). Participants mean age was 55.5 years (standard deviation [SD] 12.0); most identified as white (24, 85.7%), with Christian religious affiliations (18, 64.3%).

From February to July, 2021, 28 interviews were conducted at a mean of 9.4 (SD 1.8) months after the patient's death. While 27 participants allowed audio-recording, one preferred written notes.

### *Qualitative Analysis*

Analysis of interview data yielded insight on the experiences of families whose loved one died in hospital, organized into four categories which emphasize the concepts of sacrifice and solidarity. Participants expressed prevailing acceptance of public health policies, some with an attitude of acquiescence to restrictions for the greater good. These policies keeping loved ones at a distance had a dual effect, both exacerbating and mitigating common end-of-life care challenges within and beyond the hospital. Families universally appreciated clinician efforts to maintain compassionate care, sometimes casting their own sacrifice in solidarity with efforts that clinicians made in service to the community. They also shared adaptations to traditional post-mortem practices and rituals that influenced their grieving.

### *Acquiescence to Pandemic-Related Restrictions*

Despite the suffering and loss endured by families during the pandemic, acquiescence to the pandemic-related restrictions was acknowledged as a civic duty. Families explained how being away from their loved one during their final days reflected their recognition of the rationale for

jurisdictional rules. In surrendering their hospital visits to minimize transmission risk, many participants invoked the concept of social solidarity and safeguarding the community.

*I never abused the procedures that we had to follow. We try and understand because it was for the greater good... it was for the best... they had to take some precautions. (Partner)*

In a poignant example of accepting the risk of missing her husband’s final moments, one participant described her decision of a delayed hospital visit in terms of protecting others from possible viral transmission:

*I told [the doctor] I had been dealing with the public so I would need to go home anyhow and shower and change my clothing before I came up to the hospital and when I was enroute home, the Charge Nurse called and she said, “You know, if you do what you say you’re going to do, he may not be here.” And I said, “Well, you know, [patient’s name] would have it no other way.” He wouldn’t want me coming up and contaminating the hospital. (Partner)*

Some family members assented to the necessary restrictions, but considered the perceived changes in care as a casualty of the pandemic:

*She was in hospital there and I couldn’t visit her there and with the hearing impairment and sight impairment [it was] even harder for her because now she’s in a strange place. Everyone’s wearing PPE, which I don’t blame, and I’m sure the people couldn’t spend as much time as they may have wanted to with her because of the situation...I guess she was just collateral damage from whole COVID situation. (Son)*

**Loving and Grieving from Afar**

The experiences of being separated from a loved one during periods of critical illness and up to the moment of death were universally described as agonizing. Being kept apart led many family members to experience decisional dilemmas regarding safety for themselves and others. Participants wondered if their visits could introduce the virus, including to their dying loved one who was not infected. One participant asked himself if he should “take the risk of where I get my mother sick.” (Son) Another family member remarked on a possible conflicting sense of duty for people who would otherwise visit hospitalized patients, such as a case worker from a group

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3 home, because “*she wouldn't want to bring it back there.*” (Son).  
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6 Deprived of the chance to be physically present before and during the dying process haunted  
7 most families. Some referenced their absence at the bedside to be detrimental to a patient's  
8 recovery. While technology provided opportunities for continued connections, a few families  
9 found the virtual visits distressing, and occasionally shocking, especially witnessing the trajectory  
10 of their loved one's progressive decline. Others described difficulty understanding how much  
11 their loved one had decompensated in hospital without seeing it first-hand.  
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16  
17 *And then, we had that two-week window where we couldn't go in and then, when I pushed again*  
18 *to get in there, [my mother] was a completely different person... You couldn't get a reaction.*  
19  
20 *(Daughter)*  
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23 Some described this lack of in-person contact as impairing their ability to make informed end-of-  
24 life decisions, especially related to resuscitation directives.  
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27  
28 *You know, whatever protocol is necessary, I will follow that. I need to physically see her to make*  
29 *that decision. I can't make that decision over the phone. (Daughter)*  
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32 Families were concerned that the hardship which patients underwent were worse than theirs  
33 during the pandemic. The anguish of separation was particularly difficult for families with loved  
34 ones with physical disabilities including visual and auditory impairment. The most frequently  
35 expressed worry was about patients' ability to communicate with the care team due to sensory  
36 and/or cognitive impairments or language barriers.  
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42 *With the hearing impairments and sign impairments ... [it's] even harder for her because now*  
43 *she's in a strange place. (Son)*  
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47 While all participants grieved the loss of the chance to be physically present at the time of  
48 death, one family member acknowledged how this lack of physical presence also averted the  
49 anticipated trauma of witnessing the final moments.  
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52 *I know it sounds awful, I really wanted to be there for her, but that's a really big burden to carry*  
53 *with you for the rest of your life. (Sister)*  
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3 Imagining their loved one dying alone many months after the death during interviews, all  
4 participants expressed heartache.

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8 *I'll never know what those three weeks were like. I don't know what an eternity it was. My worst*  
9 *thing was, does he feel forsaken by us? (Partner)*  
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13 **Respect and Appreciation for Clinicians**  
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16 Families expressed gratitude for the social workers and chaplains who spent countless hours  
17 supporting them when their “world is falling apart.” (Partner) Many participants derived comfort  
18 from frequent, open communication:  
19

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22 *They always called me back. Even if it was my third call of the day, it was okay. And they gave*  
23 *me an update, whether it was ‘no change’ or whatever change it was, if there was a change. I*  
24 *didn't feel like I was bugging them. (Daughter-in-law)*  
25  
26

27  
28 Being able to rely on clinicians to deliver supportive messages to their loved one was greatly  
29 appreciated.  
30

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33 *I said, please make sure that he knows that I'm calling....that I love him very much. I care [pause]*  
34 *and that, you know, due to COVID, we can't be with him. (Partner)*  
35  
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37  
38 This family-centered contact with clinicians was greatly valued, creating connections and intimate  
39 moments whenever possible, particularly at the end:  
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43 *They did call me and ask me what I wanted to say to him before he went, if he went through the*  
44 *night. That was the biggest thing for me. (Son)*  
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48 During both in-person and virtual visits, family members observed acts of compassion performed  
49 collaboratively by nurses, often with other clinicians, such as humanizing the environment and  
50 recognizing the dignity of the patient through personal care.  
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3 *Somebody took the care to shave him properly. And, and it just put a smile on my face, you*  
4 *know, that, there was some dignity. You know that even though he was so sick, that somebody*  
5 *cared enough. I'll always remember that. Always. (Partner)*  
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### 8 9 **Post-Mortem Impacts of COVID-19**

  
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12 Many adaptations to post-mortem practices were described by those unable to visit the hospital,  
13 including identification of the body. Contrasted with typical practices of confirming a loved one's  
14 identity guided in-person by funeral home staff, one participant described a request to identify her  
15 deceased sister on a digital photo over email.  
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19  
20 *I think of what she looked like when she was dying and I think about the picture she sent me for*  
21 *confirmation, the funeral home - the picture they sent from the morgue...I haven't looked at it*  
22 *again but it's there because I don't know whether I should delete it or not. Like, it feels wrong to*  
23 *delete it but I don't want to look at it. (Sister)*  
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28 After being barred from hospital, and in some cases from long term care residences before a  
29 patient's hospitalization, funeral service limitations added another layer of loss for families who  
30 had to defer or forgo celebrations of their loved one's life.  
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35 *It feels like, if you don't have a funeral, you're not honouring her. It's just like she didn't matter.*  
36 *You know? She's just, like, in a box on the mantle and we didn't come together and talk about*  
37 *her and show our love for her. It just feels like [pause] she was just like a blip. (Sister)*  
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41 Many families described missing out on the comfort of community gatherings associated with  
42 the usual post-mortem rituals.  
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46 *When you go to funeral home and you have those two days or whatever, people come and they*  
47 *express their feelings and they comfort you, which wasn't part of this. We only had two hours at*  
48 *the funeral home and that was it. (Partner)*  
49  
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52 By contrast, exemption from social obligations during bereavement was also referred to as  
53 "blessings in disguise" (Mother, Daughter). Pandemic restrictions led to changes in conventional  
54 ceremonies, which some participants welcomed. Strict lock-down orders necessitated many  
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individuals to work from home and keep services small. Some families found relief in the permission for privacy granted by the pandemic.

*But COVID, in a weird way, was a bit of a blessing in terms of that because I have been working from home since March so I did take a little bit of time off of work. But then, you know, obviously, it's not like the week that I took off fixed everything. I was still kind of hurting from it, it was nice to be able to work and just be by myself and if I needed to, cry, you know. I'd have to like, run to the bathroom at work [pause] I could just kind of do it in my own space. (Daughter)*

Other families described domestic adaptations, having: “a celebration of life in the backyard” (Father). Some religious and secular services used video platforms. Streaming live ceremonies provided relatives opportunities to offer condolences from a distance.

*With regards to the church ceremony and also the gravesite ceremony, they broadcasted it live on FaceTime. My brother and our other family in the U.S. and back in Poland and Australia were able to watch at that time. (Son)*

Some communities came together in solidarity for hurting families. Local demonstrations of support were recounted, including an instance when a hearse carried a patient's remains to the gravesite.

*We called one of the neighbours to come [pause] they all wanted to come but they couldn't [pause] and we told them that we were going to pass by the house for his last time before going to the cemetery. And then they all stood by the front lawn saying goodbye. (Partner)*

## DISCUSSION

Findings from this study highlight the impact that the COVID-19 pandemic has had on family members who have lost a loved one in hospital. Families expressed acquiescence to pandemic-related restrictions, underscoring a sense of unity for the public good. Nevertheless, the inability to be physically present in hospital had myriad consequences for relatives and friends of dying patients. Participants described multiple distinct losses beyond the death itself, in terms of bedside vigils foregone and rushed rituals afforded by usual mourning practices. Families observed solidarity among clinical staff, and sense of unity with staff while entrusting their loved one's care to the clinical team. Although families valued clinicians' efforts to mitigate the negative impact of infection control restrictions, these efforts did not prevent their profound and enduring grief.

Family perspectives about hospitalized dying relatives during the pandemic have been reported in self-administered public surveys<sup>13 15</sup> and 2 other qualitative studies.<sup>12 16</sup> One study of 19 families of patients who died in hospital or another setting in the United Kingdom,<sup>12</sup> and a report of 19 relatives of patients who died in an intensive care units in France<sup>16</sup> also underscored the impact of physical separation on relatives' experiences of bereavement. Our findings confirm these reports of profound loss described by family members whose final connections and post-mortem rituals to honour their loved one were subverted by pandemic-related infection control measures. Delaying family contact post-mortem longer than prior research<sup>12 16</sup>, the interviews we conducted 6-16 months postmortem indicate vivid recall and suggest enduring grief. Our findings also differ from previous reports describing tension and diminished trust between families and critical care staff<sup>16</sup>, instead highlighting how connections and open communication cultivated with clinicians was a comforting aspect of their experience, perhaps facilitating bonding between families and clinicians, ultimately fostering confidence in the healthcare team.<sup>26</sup>

Contrary to the social division which can result from imposed public health restrictions,<sup>27</sup> our study differs from other research in that it revealed a general collective attitude of acceptance. Although public health policies often employ a utilitarian approach, requiring individuals to make personal sacrifices for the greater good, this tension between personal and collective interests can be further exacerbated in states of emergency.<sup>28</sup>

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Reflections on what stayed with families post-mortem illuminate some suggestions for future end-of-life practice under continuing pandemic restrictions. The angst of perceiving their loved one as dying alone,<sup>15</sup> calls for frequent, flexible, and transparent communication. Additional attention is needed for patients with language barriers or physical and/or cognitive impairments, who are especially impacted by the absence of family members. Ensuring that visual aids, hearing devices, or language translation assistance is available may aid communication for the most vulnerable, and help to alleviate family distress. Digital solutions to augment phone and in-person connections can help to share details of patients' status, trajectory, and care, but need technical and emotional preparation and support. Dedicated efforts to humanize the clinical space with personal affects, in conjunction with patient-centered acts of compassion were small yet impactful ways to comfort families from afar. Additional strategies to promote individualized patient and family-centered end-of-life care in hospital, and create personalized adaptations to memorial services and life celebrations could assist in easing family grief.

Strengths of this study include a focus on family experiences both within and beyond hospital exposure. Interview data reflect a range of relationships; the participation rate was 74%. Limitations include a predominantly white, English-speaking sample from the first pandemic wave in the context of a publicly-funded healthcare system.<sup>29</sup> Results may differ for individuals with more videoconferencing access and ability, in communities with a different COVID-19 prevalence and vaccination penetrance, and in different healthcare systems.

**Conclusion:**

This study highlights the impact of public health measures on family member experiences of the death of a hospitalized loved one. Profound loss and enduring grief were described by those whose final connections were constrained by pandemic restrictions. Despite the overwhelming sacrifices made, families reported acquiescence in the name of population health, and solidarity with clinical staff caring for their loved one. Clinicians and public health officials should consider these family-informed perspectives when generating crisis guidelines and future administrative policies to improve end-of-life care for hospitalized patients.

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For peer review only

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**Table 1: Characteristics of Family Members and Their Deceased Loved Ones**

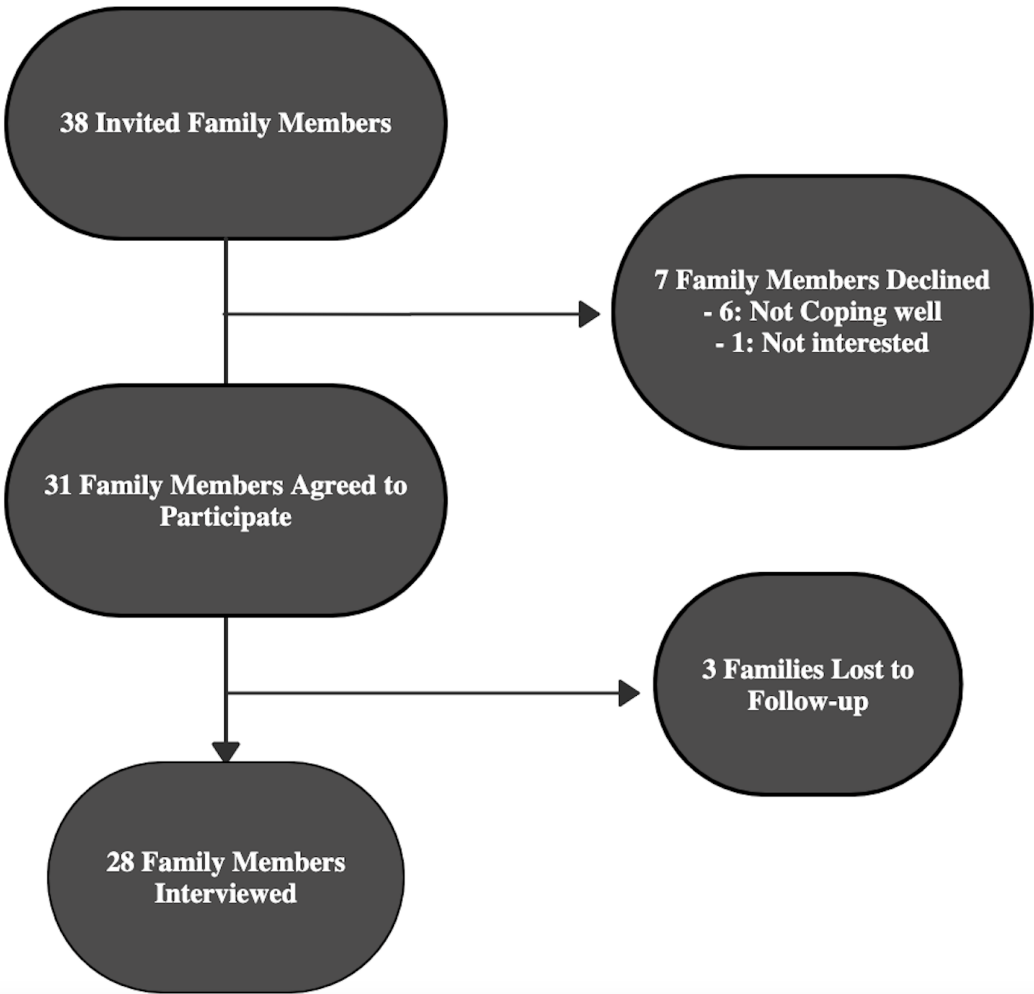
Characteristics	N=28
<b>Age, years, mean (SD)</b>	<b>55.5 (12.0)</b>
<b>Female n, (%)</b>	<b>22 (78.6)</b>
<b>Ethnicity n, (%)</b>	
White	24 (85.7)
Indigenous	2 (7.1)
Arabic	1 (3.6)
East Asian	1 (3.6)
<b>Religion n (%)</b>	
Christian	18 (64.3)
Atheist	5 (17.9)
Agnostic	4 (14.3)
Indigenous	1 (3.6)
<b>Relationship to Deceased n (%)</b>	
Child	12 (42.9)
Parent	4 (14.3)
Friend	4 (14.3)
Sibling	3 (10.7)
Partner/Spouse	2 (7.1)
Relative by Marriage (In-law)	2 (7.1)
Grandchild	1 (3.6)
<b>Ward at Patient's Time of Death n (%)</b>	
Intensive Care Unit	23 (82.1)
COVID-19 Ward	2 (7.1)
Acute Medical Stepdown Unit	1 (3.6)
Palliative Care Suite	1 (3.6)
Hospital Medical Ward	1 (3.6)

**Legend for Table 1:**

In this table we report characteristics of interviewed family members and location of the patient's death. The COVID-19 ward cared for acutely ill COVID-19 patients; those requiring high-flow nasal cannula or  $\text{FiO}_2 \geq 0.70$  were transferred to the intensive care unit.



Figure 1: Family Participant Flow Diagram



## APPENDIX A: INTERVIEW TOOL

### Interview Questions for Dying During the Pandemic: Family Experiences

The purpose of this study is to gain a deeper understanding of family members' experiences of their loved one's illness and death during COVID-19. During the interview we would like to explore how pandemic measures, use of technology, and the 3 Wishes Project may have impacted your experiences of your loved one's illness and death, as well as your own grief and bereavement. This interview is voluntary – there are no right or wrong answers. If there is a question that you would prefer not to answer please let me know. We are interested in understanding your experiences. Please feel free to share whatever seems relevant and important to you. If at any time, you need to take a break, or end the interview, please let me know.

The interview will be approximately 30-60 minutes in length. So that I can focus on our conversation and not have to take detailed notes, the interview will be audio-recorded and then transcribed verbatim to ensure that relevant information will be captured. (\*\*If using Zoom, mention that we will not be recording video during the interview – just audio.) Before we begin, I just wanted to say how sorry I am about the loss of your loved one. Can you please tell me your relationship to (patient name) OR I understand that you were (her/his) (insert role/relationship), is that right? Can I ask what you called her/him?

#### 1) Can you start by telling me about how you have been coping since then? *(respond as appropriate)*

**Sub-question: Were you provided any information on bereavement services from the hospital?**

#### 2) Please tell me about your experiences as a family member of a very sick loved one during the pandemic? (probe regarding fear, anxiety, concerns about care loved one was receiving)

**Prompt: What visiting rules were in place when your loved one was in hospital? Did the rules change over time? What was your experience with these visiting rules?**

**Sub-questions: What else was going on in your life around the time of loss? Were you working during this time, Did you feel involved in the decisions for your loved ones care?**

#### 3) In addition to the visiting rules, were there any other pandemic measures that affected the care of your loved one? (probe: issues with PPE, the ability to bring things to her/his room, issues with regards to travel for yourself or other family members)

#### 4) How often were you able to connect with your loved one?

**Prompt: Were you able to visit with your loved one in-person? If yes: can you tell me what the environment was like for your visits? Can you describe what you remember about the setting? What worked well? What didn't work well?**

**Prompt if mention is made of virtual visits: Did you visit with your loved one on the phone? On a video platform like FaceTime or Zoom? If yes: can you tell me what the environment was like for your visits? Can you describe what you remember about the setting? What worked well? What didn't work well? Is there anything you would suggest changing for future virtual visits?**

**Sub-question: In the event you were not allowed to visit, did the clinical team make efforts to have contact with you during your loved one’s final days? If yes, how was that? If yes, how often? Contact with whom on the team? Is there anything that could have been done to improve this contact? If no, what would you have liked from the clinical team during your loved one’s final days? What information would you have liked to have had?**

**Sub-question: Were you able to be present at the time of death? How were you present? What was that like?**

**5) Were there any sources of comfort either for you or your loved one during their last days? If yes, can you tell me about them? If no, is there anything specific that would have given them comfort?**

**6) Were you able to arrange a funeral or memorial service for your loved one?**

**If yes, what did that look like? Did the hospital offer any advice about services during the pandemic? Can you tell me about the experience of organizing and attending that service? What things, if any, were different because of the pandemic?**

**If no, are there plans to hold a service in the future?**

**7) It is always challenging to say goodbye to a loved one at the end of life. How did the pandemic protocols impact how you said goodbye to your loved one? How did you feel about this?**

**8) When your loved one was in hospital, are you aware of anything special that staff arranged for them?**

**If yes, could you give me some examples? How did those ideas come up? Who made them happen? Did you have the opportunity to suggest anything? Did these efforts influence your experience of your loved one’s death? Did you ever hear about the 3 Wishes Project? If so, what did you learn about it?**

**If no, is there anything you think could have improved your experience with having your loved one die in hospital during the pandemic?**

**9) Is there anything else that you would like to tell me about your experience of having a loved one die in hospital during the pandemic?**

**10) Do you have any suggestions for the clinical team about caring for dying patients and their families during the pandemic or other times in the future when visiting restrictions are needed?**

**I would like to sincerely thank you for being so open and telling us about your experience as a family member of a hospitalized patient during the pandemic. Before we end the interview, I have a few demographic questions to ask you which will help us describe as a group, the family members who participated in our study. If you do not feel comfortable answering you can say no, or pass.**

*Participant Age: \_\_; Identified Gender: \_\_\_\_\_; Religion: \_\_\_\_\_; Ethnicity: \_\_\_\_\_; Relationship to Deceased Patient: \_\_\_\_\_*

**Thank you again for participating in this interview. END**

# BMJ Open

## Sacrifice and Solidarity: A Qualitative Study of Family Experiences of Death and Bereavement in Critical Care Settings During the Pandemic

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**Sacrifice and Solidarity:  
A Qualitative Study of Family Experiences of Death and Bereavement in Critical Care  
Settings During the Pandemic**

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Dionne<sup>1,4</sup>, Andrew Cheung<sup>1</sup>, France Clarke<sup>4</sup>, Neala Hoad<sup>5</sup>, Anne Boyle<sup>2</sup>, Jessica Huynh<sup>1</sup>,  
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for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

**Transparency Statement:** Dr. Brittany B. Dennis affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned (and, if relevant, registered) have been explained.

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**Data Availability Statement**

No data is available for public use. This study includes qualitative data generated from interviews with families. To protect the confidentiality of families included in this study we will not be sharing data gained from interview. Families included in this work did not agree for data generated from interviews to be shared and publicly available.

**Author Contribution Statement:**

All authors (BBD, DJC, MV, MS, DBV, AB, TV, JCD, AC, FC, NH, JH, TN, FT, MS, & KF) made equal contributions to the analysis and interpretation of the data. BBD, DJC, and MV were responsible for the conception and design of the study. MS and BBD were responsible for the acquisition of the data. DJC, BBD, MS, and TN, MV were responsible for the analysis of the data. All authors reviewed and contributed to the final draft of the manuscript. All authors approve the current submission.

## ABSTRACT

### Background:

Pandemic-related restrictions are expected to continue to shape end-of-life care and impact the experiences of dying hospitalized patients and their families.

### Objective:

To understand families' experiences of loss and bereavement during and after the death of their loved one amidst the SARS-CoV-2 (COVID-19) pandemic.

### Design:

Qualitative descriptive study.

### Setting:

Three acute care units in a Canadian tertiary care hospital.

### Participants:

Family members of 28 hospitalized patients who died from March-July 2020.

### Main outcome measures:

Qualitative semi-structured interviews conducted 6-16 months after patient death inquired about family experiences before and beyond the death of their loved one, and garnered suggestions to improve end-of-life care.

### Results:

Pandemic restrictions had consequences for families of dying hospitalized patients. Most family members described an attitude of acquiescence, some framing their experience as a sacrifice made for the public good. Families appreciated how clinicians engendered trust in the name of social solidarity while trying to mitigate the negative impact of family separation. However, fears about the patient's experience of isolation and changes to post-mortem rituals also created despair and contributed to long-lasting grief.

### Conclusion:



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Profound loss and enduring grief were described by family members whose final connections to their loved one were constrained by pandemic circumstances. Families observed solidarity among clinical staff, and experienced a sense of unity with staff, which alleviated some distress. Their suggestions to improve end-of-life care given pandemic restrictions included frequent, flexible communication, exceptions for family presence when safe, and targeted efforts to connect patients whose isolation is intensified by functional impairment or limited technologic access.

**Strengths and Limitations of this Study**

Strengths of this study include a focus on family experiences of loss and bereavement both within and beyond hospital exposure.

Results from this work garnered suggestions for improving end-of-life care during pandemic times, which included frequent, flexible, and transparent communication to help alleviate distressing images of patients dying alone as well as targeted attention for patients with language barriers or physical and/or cognitive impairments, who are especially impacted by the absence of their family.

This study extends prior work in a larger sample of 28 families in the North American setting, with a higher participation rate and range of relationships.

Limitations include a predominantly white, English-speaking sample from the first pandemic wave in the context of a publicly-funded healthcare system.

Results may differ for individuals with more videoconferencing access and ability, in communities with a different COVID-19 prevalence and vaccination penetrance, and in different healthcare systems.

## Introduction

As mortality associated with serious SARS-CoV-2 (COVID-19) infection continues,<sup>1-5</sup> so do public health measures that restrict family presence in hospital.<sup>6</sup> Minimal personal contact and maximal barrier precautions profoundly affect the experiences of living, visiting and dying in hospital.<sup>6</sup> While facilitating an intimate environment for compassionate end-of-life care can be difficult at the best of times, the COVID-19 pandemic has made providing personalized care for dying patients and their families more challenging.<sup>7-10</sup>

With ongoing infection rates, pandemic restrictions are expected to impact hospitalized patients, their families, and healthcare providers for months to come.<sup>11</sup> Research is beginning to emerge directly from family members on the impact of losing a loved one during the pandemic.<sup>12-17</sup> In a Veterans Affairs (VA) survey, families of dying patients in acute hospital care, nursing home, and hospice settings reported poor communication with the healthcare team and fear of patients dying alone as leading contributors to their experiences of distress.<sup>15</sup> Other qualitative work investigating the experiences of grieving family members describe suffering driven by the separation from their loved ones, an inability to establish strong bonds with staff, and an interruption of common death rituals.<sup>12 16</sup> The forced separation of patients from their family has also troubled clinicians worldwide.<sup>10 18-21</sup>

Given the tension between pandemic public health mandates and the desire of many relatives to visit their hospitalized family member, the objective of this study was to understand experiences of loss and bereavement for families of dying patients during the pandemic and garner suggestions for comforting practices in this context.

## Methods

In this post-positivist qualitative descriptive study,<sup>22 23</sup> we contacted families of patients who died in hospital during the first wave of the COVID-19 pandemic between March 16 to July 1, 2020 in three acute care units (ICU, medical step down, COVID-19 ward) at a university-affiliated hospital in Canada. Following a study of hospital-based clinicians to understand adaptations to end-of-life care during the pandemic<sup>10</sup>, family members of those patients were invited by telephone to an interview to understand how their experience of loss and bereavement was influenced by the pandemic. We attempted to recruit one family member or

friend as the designated next-of-kin for each patient based on documentation in the medical chart. Family member recruitment was delayed 6-12 months after the patient's death to honour the anticipated grieving process.

Employing qualitative description methods,<sup>23</sup> we used a semi-structured interview guide developed and piloted with our interprofessional research team (supplementary appendix) who have expertise in critical care medicine, nursing, and respiratory therapy, qualitative research, and spiritual care. Domains included: general experiences of loss and bereavement; influences of pandemic-related hospital policies; videoconferencing technology, and memorial rituals. Interviews were conducted by two trained female interviewers (BD, MS), one of whom is a resident physician (BD). Participants were given the choice of being interviewed by telephone or videoconferencing, and of having their interview audio-recorded or having notes taken in place of recording. Verbal informed consent was recorded prior to the interview. Demographic data were captured using open-ended questions.

*Data Analysis*

Transcripts were analyzed using conventional qualitative content analysis.<sup>24</sup> After an initial phase of open coding to condense and summarize the data, focused codes were developed through discussion with the research team. New data were compared to emerging analytic concepts for refinement using a constant comparative approach <sup>25</sup> during serial investigator meetings. Rigour was ensured by triangulating findings between analysts and participants, and through the development of memos through the data collection and analysis process to form an audit trail.<sup>26 27</sup> Descriptive statistics were used to quantitatively summarize family demographic data.

*Ethics*

Local research ethics approval was obtained from the Hamilton Integrated Research Ethics Board (HiREB-11005) and all interviewees provided informed consent.

*Role of Funding*

This study received peer-review funding by Physicians Services Incorporated of Ontario (Grant R21-16), McMaster University Paul O'Byrne Research Grant, and the Canadian

Institutes for Health Research. The funders had no role in study design and conduct of the study; collection, management, analysis, and interpretation of the data; or preparation, review, or approval of the manuscript.

### *Patient and Public Involvement*

Patient and public involvement were sought during the development of the original 3 Wishes Project protocol.<sup>10</sup> The 3 Wishes Project is an end-of-life intervention aimed to honour dying patients and support families in grief. It has grown into a program of research aimed at improving EOL care across critical and acute care settings.<sup>28-30</sup> Many studies have emerged from the larger multicenter research program,<sup>28-30</sup> demonstrating feasibility, scalability, transferability and value. Due to expedited study processes during the COVID-19 pandemic, dying patients, their loved ones, and the public were not directly involved in the design of this study.

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3 **RESULTS**  
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6 ***Participants***  
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9 Of 45 deceased patients included in the original study,<sup>10</sup> we were unable to locate a surrogate  
10 decision-maker for 7 patients (e.g. no family, changed addresses, no telephone). We contacted  
11 family members for 38 patients (Figure 1). Of these, 7 (18.4%) declined to participate, 1 due to  
12 lack of interest and 6 explaining their difficulty coping with the death of their loved one. Of 31  
13 family members who agreed to participate, 3 (9.7%) interviews were not completed due to loss  
14 to follow-up. Of 28 family members interviewed, 2 were partners, 4 were parents, 14 were  
15 children, and 8 had other relationships with the deceased (Table 1). Participants mean age was  
16 55.5 years (standard deviation [SD] 12.0); most identified as white (24, 85.7%), with Christian  
17 religious affiliations (18, 64.3%).  
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25 From February to July, 2021, 28 interviews were conducted at a mean of 9.4 (SD 1.8) months  
26 after the patient's death. While 27 participants allowed audio-recording, one preferred written  
27 notes.  
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31 ***Qualitative Analysis***  
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34 Analysis of interview data yielded insight on the experiences of families whose loved one died in  
35 hospital, organized into four categories which emphasize the concepts of sacrifice and  
36 solidarity. Participants expressed prevailing acceptance of public health policies, some with an  
37 attitude of acquiescence to restrictions for the greater good. These policies keeping loved ones  
38 at a distance had a dual effect, both exacerbating and mitigating common end-of-life care  
39 challenges within and beyond the hospital. Families universally appreciated clinician efforts to  
40 maintain compassionate care, sometimes casting their own sacrifice in solidarity with efforts that  
41 clinicians made in service to the community. They also shared adaptations to traditional post-  
42 mortem practices and rituals that influenced their grieving.  
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50 ***Acquiescence to Pandemic-Related Restrictions***  
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52 Despite the suffering and loss endured by families during the pandemic, acquiescence to the  
53 pandemic-related restrictions was acknowledged as a civic duty. Families explained how being  
54 away from their loved one during their final days reflected their recognition of the rationale for  
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jurisdictional rules. In surrendering their hospital visits to minimize transmission risk, many participants invoked the concept of social solidarity and safeguarding the community.

*I never abused the procedures that we had to follow. We try and understand because it was for the greater good... it was for the best... they had to take some precautions. (Partner)*

In a poignant example of accepting the risk of missing her husband's final moments, one participant described her decision of a delayed hospital visit in terms of protecting others from possible viral transmission:

*I told [the doctor] I had been dealing with the public so I would need to go home anyhow and shower and change my clothing before I came up to the hospital and when I was enroute home, the Charge Nurse called and she said, "You know, if you do what you say you're going to do, he may not be here." And I said, "Well, you know, [patient's name] would have it no other way." He wouldn't want me coming up and contaminating the hospital. (Partner)*

Some family members assented to the necessary restrictions, but considered the perceived changes in care as a casualty of the pandemic:

*She was in hospital there and I couldn't visit her there and with the hearing impairment and sight impairment [it was] even harder for her because now she's in a strange place. Everyone's wearing PPE, which I don't blame, and I'm sure the people couldn't spend as much time as they may have wanted to with her because of the situation...I guess she was just collateral damage from whole COVID situation. (Son)*

### **Loving and Grieving from Afar**

The experiences of being separated from a loved one during periods of critical illness and up to the moment of death were universally described as agonizing. Being kept apart led many family members to experience decisional dilemmas regarding safety for themselves and others. Participants wondered if their visits could introduce the virus, including to their dying loved one who was not infected. One participant asked himself if he should *"take the risk of where I get my mother sick."* (Son) Another family member remarked on a possible conflicting sense of duty for people who would otherwise visit hospitalized patients, such as a case worker from a group

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home, because “*she wouldn't want to bring it back there.*” (Son).

Deprived of the chance to be physically present before and during the dying process haunted most families. Some referenced their absence at the bedside to be detrimental to a patient’s recovery. While technology provided opportunities for continued connections, a few families found the virtual visits distressing, and occasionally shocking, especially witnessing the trajectory of their loved one’s progressive decline. Others described difficulty understanding how much their loved one had decompensated in hospital without seeing it first-hand.

*And then, we had that two-week window where we couldn't go in and then, when I pushed again to get in there, [my mother] was a completely different person... You couldn't get a reaction.*  
(Daughter)

Some described this lack of in-person contact as impairing their ability to make informed end-of-life decisions, especially related to resuscitation directives.

*You know, whatever protocol is necessary, I will follow that. I need to physically see her to make that decision. I can't make that decision over the phone.* (Daughter)

Families were concerned that the hardship which patients underwent were worse than theirs during the pandemic. The anguish of separation was particularly difficult for families with loved ones with physical disabilities including visual and auditory impairment. The most frequently expressed worry was about patients’ ability to communicate with the care team due to sensory and/or cognitive impairments or language barriers.

*With the hearing impairments and sign impairments ... [it's] even harder for her because now she's in a strange place.* (Son)

While all participants grieved the loss of the chance to be physically present at the time of death, one family member acknowledged how this lack of physical presence also averted the anticipated trauma of witnessing the final moments.

*I know it sounds awful, I really wanted to be there for her, but that's a really big burden to carry with you for the rest of your life.* (Sister)

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3 Imagining their loved one dying alone many months after the death during interviews, all  
4 participants expressed heartache.

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8 *I'll never know what those three weeks were like. I don't know what an eternity it was. My worst*  
9 *thing was, does he feel forsaken by us? (Partner)*  
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### 11 12 **Respect and Appreciation for Clinicians**

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15 Families expressed gratitude for the social workers and chaplains who spent countless hours  
16 supporting them when their “*world is falling apart.*” (Partner) Many participants derived comfort  
17 from frequent, open communication:  
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22 *They always called me back. Even if it was my third call of the day, it was okay. And they gave*  
23 *me an update, whether it was ‘no change’ or whatever change it was, if there was a change. I*  
24 *didn't feel like I was bugging them. (Daughter-in-law)*  
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28 Being able to rely on clinicians to deliver supportive messages to their loved one was greatly  
29 appreciated.  
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33 *I said, please make sure that he knows that I'm calling....that I love him very much. I care [pause]*  
34 *and that, you know, due to COVID, we can't be with him. (Partner)*  
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38 This family-centered contact with clinicians was greatly valued, creating connections and intimate  
39 moments whenever possible, particularly at the end:  
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43 *They did call me and ask me what I wanted to say to him before he went, if he went through the*  
44 *night. That was the biggest thing for me. (Son)*  
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48 During both in-person and virtual visits, family members observed acts of compassion performed  
49 collaboratively by nurses, often with other clinicians, such as humanizing the environment and  
50 recognizing the dignity of the patient through personal care.  
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*Somebody took the care to shave him properly. And, and it just put a smile on my face, you know, that, there was some dignity. You know that even though he was so sick, that somebody cared enough. I'll always remember that. Always. (Partner)*

**Post-Mortem Impacts of COVID-19**

Many adaptations to post-mortem practices were described by those unable to visit the hospital, including identification of the body. Contrasted with typical practices of confirming a loved one's identity guided in-person by funeral home staff, one participant described a request to identify her deceased sister on a digital photo over email.

*I think of what she looked like when she was dying and I think about the picture she sent me for confirmation, the funeral home - the picture they sent from the morgue...I haven't looked at it again but it's there because I don't know whether I should delete it or not. Like, it feels wrong to delete it but I don't want to look at it. (Sister)*

After being barred from hospital, and in some cases from long term care residences before a patient's hospitalization, funeral service limitations added another layer of loss for families who had to defer or forgo celebrations of their loved one's life.

*It feels like, if you don't have a funeral, you're not honouring her. It's just like she didn't matter. You know? She's just, like, in a box on the mantle and we didn't come together and talk about her and show our love for her. It just feels like [pause] she was just like a blip. (Sister)*

Many families described missing out on the comfort of community gatherings associated with the usual post-mortem rituals.

*When you go to funeral home and you have those two days or whatever, people come and they express their feelings and they comfort you, which wasn't part of this. We only had two hours at the funeral home and that was it. (Partner)*

By contrast, exemption from social obligations during bereavement was also referred to as "blessings in disguise" (Mother, Daughter). Pandemic restrictions led to changes in conventional ceremonies, which some participants welcomed. Strict lock-down orders necessitated many

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3 individuals to work from home and keep services small. Some families found relief in the  
4 permission for privacy granted by the pandemic.  
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8 *But COVID, in a weird way, was a bit of a blessing in terms of that because I have been working*  
9 *from home since March so I did take a little bit of time off of work. But then, you know, obviously,*  
10 *it's not like the week that I took off fixed everything. I was still kind of hurting from it, it was nice to*  
11 *be able to work and just be by myself and if I needed to, cry, you know. I'd have to like, run to the*  
12 *bathroom at work [pause] I could just kind of do it in my own space. (Daughter)*  
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17 Other families described domestic adaptations, having: “a celebration of life in the backyard”  
18 (Father). Some religious and secular services used video platforms. Streaming live ceremonies  
19 provided relatives opportunities to offer condolences from a distance.  
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24 *With regards to the church ceremony and also the gravesite ceremony, they broadcasted it live*  
25 *on FaceTime. My brother and our other family in the U.S. and back in Poland and Australia were*  
26 *able to watch at that time. (Son)*  
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30 Some communities came together in solidarity for hurting families. Local demonstrations of  
31 support were recounted, including an instance when a hearse carried a patient's remains to the  
32 gravesite.  
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36 *We called one of the neighbours to come [pause] they all wanted to come but they couldn't*  
37 *[pause] and we told them that we were going to pass by the house for his last time before going*  
38 *to the cemetery. And then they all stood by the front lawn saying goodbye. (Partner)*  
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DISCUSSION

Findings from this study highlight the impact that the COVID-19 pandemic has had on family members who have lost a loved one in hospital. Families expressed acquiescence to pandemic-related restrictions, underscoring a sense of unity for the public good. Nevertheless, the inability to be physically present in hospital had myriad consequences for relatives and friends of dying patients. Participants described multiple distinct losses beyond the death itself, in terms of bedside vigils foregone and rushed rituals afforded by usual mourning practices. Families observed solidarity among clinical staff, and sense of unity with staff while entrusting their loved one’s care to the clinical team. Although families valued clinicians’ efforts to mitigate the negative impact of infection control restrictions, these efforts did not prevent their profound and enduring grief.

Family perspectives about hospitalized dying relatives during the pandemic have been reported in self-administered public surveys<sup>13 15</sup> and 2 other qualitative studies.<sup>12 16</sup> One study of 19 families of patients who died in hospital or another setting in the United Kingdom,<sup>12</sup> and a report of 19 relatives of patients who died in an intensive care units in France <sup>16</sup> also underscored the impact of physical separation on relatives’ experiences of bereavement. Our findings confirm these reports of profound loss described by family members whose final connections and post-mortem rituals to honour their loved one were subverted by pandemic-related infection control measures. Delaying family contact post-mortem longer than prior research<sup>12 16</sup>, the interviews we conducted 6-16 months postmortem indicate vivid recall and suggest enduring grief. Our findings also differ from previous reports describing tension and diminished trust between families and critical care staff<sup>16</sup>, instead highlighting how connections and open communication cultivated with clinicians was a comforting aspect of their experience, perhaps facilitating bonding between families and clinicians, ultimately fostering confidence in the healthcare team.<sup>31</sup>

Contrary to the social division which can result from imposed public health restrictions,<sup>32</sup> our study differs from other research in that it revealed a general collective attitude of acceptance. Although public health policies often employ a utilitarian approach, requiring individuals to make personal sacrifices for the greater good, this tension between personal and collective interests can be further exacerbated in states of emergency.<sup>33</sup>

Reflections on what stayed with families post-mortem illuminate some suggestions for future end-of-life practice under continuing pandemic restrictions. The angst of perceiving their loved one as dying alone,<sup>15</sup> calls for frequent, flexible, and transparent communication. Additional attention is needed for patients with language barriers or physical and/or cognitive impairments, who are especially impacted by the absence of family members. Ensuring that visual aids, hearing devices, or language translation assistance is available may aid communication for the most vulnerable, and help to alleviate family distress. Digital solutions to augment phone and in-person connections can help to share details of patients' status, trajectory, and care, but need technical and emotional preparation and support. Dedicated efforts to humanize the clinical space with personal affects, in conjunction with patient-centered acts of compassion were small yet impactful ways to comfort families from afar. Additional strategies to promote individualized patient and family-centered end-of-life care in hospital, and create personalized adaptations to memorial services and life celebrations could assist in easing family grief.

Strengths of this study include a focus on family experiences both within and beyond hospital exposure. Interview data reflect a range of relationships; the participation rate was 74%. Limitations include a predominantly white, English-speaking sample from the first pandemic wave in the context of a publicly-funded healthcare system.<sup>34</sup> Results may differ for individuals with more videoconferencing access and ability, in communities with a different COVID-19 prevalence and vaccination penetrance, and in different healthcare systems.

## Conclusion:

This study highlights the impact of public health measures on family member experiences of the death of a hospitalized loved one. Profound loss and enduring grief were described by those whose final connections were constrained by pandemic restrictions. Despite the overwhelming sacrifices made, families reported acquiescence in the name of population health, and solidarity with clinical staff caring for their loved one. Clinicians and public health officials should consider these family-informed perspectives when generating crisis guidelines and future administrative policies to improve end-of-life care for hospitalized patients.

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**Acknowledgments:**

We honour the lives of each patient who died during the pandemic. We are grateful to the families who so graciously shared their perspectives with us. We appreciate Dr. Jill Rudkowski and Alyson Takaoka for their support in both organizing and initiating this project, and value the nurses, physicians, respiratory therapists, physical therapists, social workers, chaplains and other clinicians caring for patients throughout this pandemic.

Figure Legend

Figure 1: Family Participant Flow Diagram

Caption Figure 1: Summary of recruitment flow for eligible families

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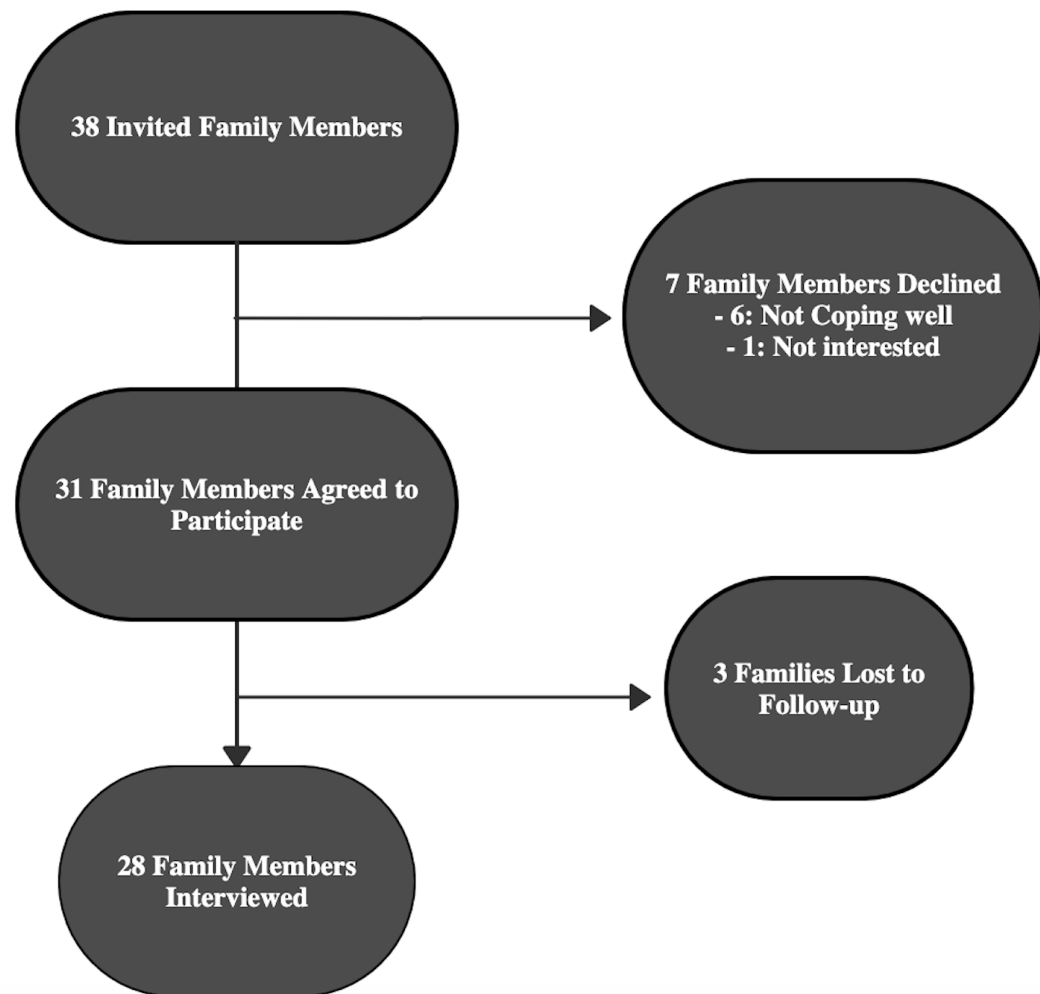


Table 1: Characteristics of Family Members and Their Deceased Loved Ones

Characteristics	N=28
Age, years, mean (SD)	55.5 (12.0)
Female n, (%)	22 (78.6)
Ethnicity n, (%)	
White	24 (85.7)
Indigenous	2 (7.1)
Arabic	1 (3.6)
East Asian	1 (3.6)
Religion n (%)	
Christian	18 (64.3)
Atheist	5 (17.9)
Agnostic	4 (14.3)
Indigenous	1 (3.6)
Relationship to Deceased n (%)	
Child	12 (42.9)
Parent	4 (14.3)
Friend	4 (14.3)
Sibling	3 (10.7)
Partner/Spouse	2 (7.1)
Relative by Marriage (In-law)	2 (7.1)
Grandchild	1 (3.6)
Ward at Patient's Time of Death n (%)	
Intensive Care Unit	23 (82.1)
COVID-19 Ward	2 (7.1)
Acute Medical Stepdown Unit	1 (3.6)
Palliative Care Suite	1 (3.6)
Hospital Medical Ward	1 (3.6)

**Legend for Table 1:**  
In this table we report characteristics of interviewed family members and location of the patient's death. The COVID-19 ward cared for acutely ill COVID-19 patients; those requiring high-flow nasal cannula or FiO2 ≥ 0.70 were transferred to the intensive care unit.

**Figure 1: Family Participant Flow Diagram**



**APPENDIX A: INTERVIEW TOOL**

**Interview Questions for Dying During the Pandemic: Family Experiences**

The purpose of this study is to gain a deeper understanding of family members’ experiences of their loved one’s illness and death during COVID-19. During the interview we would like to explore how pandemic measures, use of technology, and the 3 Wishes Project may have impacted your experiences of your loved one’s illness and death, as well as your own grief and bereavement. This interview is voluntary – there are no right or wrong answers. If there is a question that you would prefer not to answer please let me know. We are interested in understanding your experiences. Please feel free to share whatever seems relevant and important to you. If at any time, you need to take a break, or end the interview, please let me know.

The interview will be approximately 30-60 minutes in length. So that I can focus on our conversation and not have to take detailed notes, the interview will be audio-recorded and then transcribed verbatim to ensure that relevant information will be captured. (\*\*If using Zoom, mention that we will not be recording video during the interview – just audio.) Before we begin, I just wanted to say how sorry I am about the loss of your loved one. Can you please tell me your relationship to (patient name) OR I understand that you were (her/his) (insert role/relationship), is that right? Can I ask what you called her/him?

**1) Can you start by telling me about how you have been coping since then? (*respond as appropriate*)**

**Sub-question: Were you provided any information on bereavement services from the hospital?**

**2) Please tell me about your experiences as a family member of a very sick loved one during the pandemic? (probe regarding fear, anxiety, concerns about care loved on was receiving)**

**Prompt: What visiting rules were in place when your loved one was in hospital? Did the rules change over time? What was your experience with these visiting rules?**

**Sub-questions: What else was going on in your life around the time of loss? Were you working during this time, Did you feel involved in the decisions for your loved ones care?**

**3) In addition to the visiting rules, were there any other pandemic measures that affected the care of your loved one? (probe: issues with PPE, the ability to bring things to her/his room, issues with regards to travel for yourself or other family members)**

**4) How often were you able to connect with your loved one?**

**Prompt: Were you able to visit with your loved one in-person? If yes: can you tell me what the environment was like for your visits? Can you describe what you remember about the setting? What worked well? What didn’t work well?**

**Prompt if mention is made of virtual visits: Did you visit with your loved one on the phone? On a video platform like FaceTime or Zoom? If yes: can you tell me what the environment was like for your visits? Can you describe what you remember about the setting? What worked well? What didn’t work well? Is there anything you would suggest changing for future virtual visits?**

**Sub-question: In the event you were not allowed to visit, did the clinical team make efforts to have contact with you during your loved one's final days? If yes, how was that? If yes, how often? Contact with whom on the team? Is there anything that could have been done to improve this contact? If no, what would you have liked from the clinical team during your loved one's final days? What information would you have liked to have had?**

**Sub-question: Were you able to be present at the time of death? How were you present? What was that like?**

**5) Were there any sources of comfort either for you or your loved one during their last days? If yes, can you tell me about them? If no, is there anything specific that would have given them comfort?**

**6) Were you able to arrange a funeral or memorial service for your loved one?**

**If yes, what did that look like? Did the hospital offer any advice about services during the pandemic? Can you tell me about the experience of organizing and attending that service? What things, if any, were different because of the pandemic?**

**If no, are there plans to hold a service in the future?**

**7) It is always challenging to say goodbye to a loved one at the end of life. How did the pandemic protocols impact how you said goodbye to your loved one? How did you feel about this?**

**8) When your loved one was in hospital, are you aware of anything special that staff arranged for them?**

**If yes, could you give me some examples? How did those ideas come up? Who made them happen? Did you have the opportunity to suggest anything? Did these efforts influence your experience of your loved one's death? Did you ever hear about the 3 Wishes Project? If so, what did you learn about it?**

**If no, is there anything you think could have improved your experience with having your loved one die in hospital during the pandemic?**

**9) Is there anything else that you would like to tell me about your experience of having a loved one die in hospital during the pandemic?**

**10) Do you have any suggestions for the clinical team about caring for dying patients and their families during the pandemic or other times in the future when visiting restrictions are needed?**

**I would like to sincerely thank you for being so open and telling us about your experience as a family member of a hospitalized patient during the pandemic. Before we end the interview, I have a few demographic questions to ask you which will help us describe as a group, the family members who participated in our study. If you do not feel comfortable answering you can say no, or pass.**

*Participant Age: \_\_; Identified Gender: \_\_\_\_\_; Religion: \_\_\_\_\_; Ethnicity: \_\_\_\_\_; Relationship to Deceased Patient: \_\_\_\_\_*

**Thank you again for participating in this interview. END**

Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	3

Introduction

<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	5
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	5

Methods

<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5
<b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6
<b>Context</b> - Setting/site and salient contextual factors; rationale**	5,6
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	5,6
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6

<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6
<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	8
<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6
<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6
<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6

### Results/findings

<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	8
<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	8-13

### Discussion

<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	14
<b>Limitations</b> - Trustworthiness and limitations of findings	15

### Other

<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	1
<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	1-2

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**  
O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388

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